

Montana's Children's Autism Waiver (CAW) Report:
Initial Outcomes of Cohort One
(Full Report)

January 2013

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Overview

In 2009, the Developmental Disabilities Program (DDP) within Montana's Department of Public Health and Human Services (DPHHS) implemented the Medicaid-funded Children's Autism Waiver (CAW) to provide a three year, intensive, behavioral program for young children diagnosed with Autism Spectrum Disorders (ASD) and their families. At the start of the program, a plan to evaluate services was also created. This report is the result of the CAW program and the evaluation project. Specifically, this report is guided by the *Montana Autism Evaluation Plan* (Garfinkle & McGregor, 2010) and provides information on the first group of children to complete the CAW program.

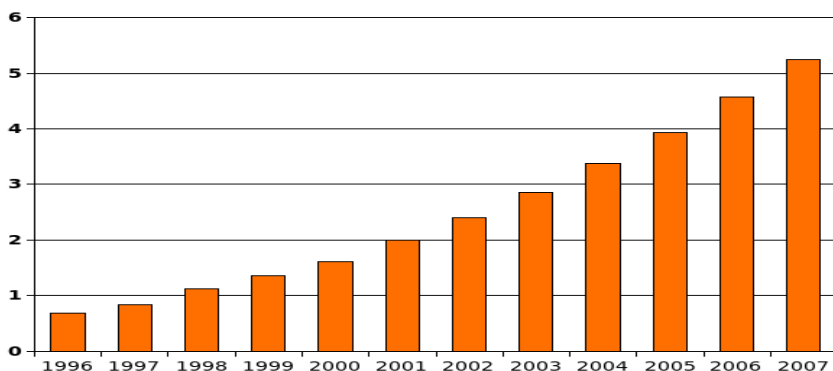
The *Montana Autism Evaluation Plan* (Garfinkle & McGregor, 2010) focused on evaluating the program, child outcomes, family outcomes, program outcomes, and provider outcomes. By evaluating these topics, DPHHS thought a full picture of the outcomes of the program could be described. Each topic will be addressed in turn. Where appropriate, measures used will be described, data will be presented, and analysis will be provided. In some cases, outcomes will be placed in a bigger context for comparison and finally, recommendations for future planning will be made.

Background

Montana pursued a Medicaid waiver to more effectively address the needs of children diagnosed with ASD and their families. ASD is a life-long developmental disability that affects one's social and communication skills. Additionally, people diagnosed with ASD have a restrictive repertoire of behavior. Restrictive repertoire for individuals with ASD is described as either a contracted range of interests (e.g., being interested in only the wheels of a toy car, not the entire toy car) or as self-stimulatory behavior (e.g., rocking or hand flapping). Currently, ASD is diagnosed through behavioral examination, as no medical tests exist. And, no cure exists. However, it is well established that with intensive, behavioral intervention, nearly half of the children make good progress (Dawson, 2012; Howlin, 2005; Reichow & Wolery, 2009).

During the years Montana was developing and seeking approval for the CAW, the prevalence rate of ASD was 1 in 110 live births. This rate represented an increase from historical numbers, as depicted in Figure 1. Figure 1 is a bar chart that represents the number of children aged 6–17 (per 1,000 U.S. resident children aged 6–17) who were served under the Individuals with Disabilities Education Act (IDEA) with autism, from 1996 through 2007. It illustrates the increase in children diagnosed with ASD.

Figure 1. Number of children, per 1,000, diagnosed with ASD by year.



(<http://en.wikipedia.org/wiki/File:US-autism-6-17-1996-2007.png>, 2012)

Since the CAW has been implemented, prevalence rates have continued to increase. The Centers for Disease Control and Prevention estimates that the prevalence rate is now 1 in 88 live births (CDC, 2012). ASD is four to five times more common in boys than in girls and has been documented in all racial, ethnic, and socioeconomic groups (CDC, 2012). ASD is more common in children than pediatric AIDS, diabetes and cancer combined (Autism Speaks, 2012). Children have been diagnosed with ASD across our state in all five of Montana's Developmental Disabilities Program service regions (see Appendix A – Map of CAW Cohort 1 Family Locations).

Overview of CAW

In order to be eligible for CAW services, a child must first be diagnosed with ASD and have a significant delay in adaptive behaviors. Adaptive behaviors are age-appropriate skills necessary for people to live and function safely and appropriately in daily life. These are real life skills such as grooming, dressing, safety, safe food handling, following school rules, money management, cleaning, making friends, social skills, and personal responsibility.

Diagnoses were made in one of two ways. Either the child was directly examined by one of the regional DDP Evaluation and Diagnosis (E&D) clinics. Or, for children with an existing diagnosis, the E&D team reviewed the child's existing medical records. A total of 288 (223 of which were male and 65 of which were female) children were diagnosed as eligible for the CAW. Using a stratified sample weighted by region (i.e., the total number of program slots were allocated to the region based on percentage of state population, from there a random draw for each region is held), children were selected for participation. For the first participants in the CAW (called throughout this document "Cohort 1") in order to maintain all 50 program places, a total of 65 children were drawn over the three years. Of those, 15 families declined or withdrew from service. The most common reason was family time commitment required for the program, followed by families who have moved, and then families who had accessed services through other avenues (i.e., insurance services, other government services or private pay). A total of 104 children have aged off the waitlist (e.g., have turned five years old without being drawn and are therefore no longer eligible to be selected for CAW services). Currently all program slots are filled (with Cohort 2 participants) and there is a waiting list of 65 children.

Evaluation: Program Performance

The first focus area for evaluation is program performance. The rationale for this first focus area is that it is important to insure the program was capable of delivering services as described in the Waiver application document. Outcomes of participants cannot be attributed to the program if the program itself cannot be described. In this focus area there are two questions: 1) "What type of services are being delivered through the CAW program?" and 2) "Are interventions developed for children served by the CAW implemented with fidelity?"

In order to answer "What type of services are being delivered through the CAW program?" data were collected on a key variables.

The core services of the waiver program are case management, Program Design and Monitoring, and Children's Autism Trainer. Ancillary capped services include transportation, respite, environmental modifications/adaptive equipment, and speech, occupational, and physical therapy.

Case management services assist individuals in gaining access to needed medical, social, educational services and other resources and supports. Case management includes the following

assistance: 1) comprehensive assessment and periodic reassessment of individual needs to determine the need for services; 2) development (and periodic revision) of an individual family support care plan; 3) referral and related activities to help an eligible individual obtain needed services; 4) monitoring and follow-up activities; and, 5) crisis supports.

Program Design and Monitoring (PDM) staff (a Family Support Specialist with an autism endorsement or a Board Certified Behavioral Analyst) develop individualized formal written training plans and protocols using evidence-based training approaches based on Applied Behavior Analysis. This plan is used by the Children's Autism Trainer to help the child acquire, retain, and generalize self-help, socialization, cognitive, communication, organizational skills and positive behaviors necessary to function successfully in home and community based settings.

Children's Autism Training (CAT) is a direct training service which provides hands on training using evidence-based Applied Behavior Analysis practices and methods. Staff providing CAT services is trained by the person providing Program Design and Monitoring (PDM) services and follows specific written individualized training protocols developed by PDM staff in working with and training the child.

One important aspect of the program is the actual number of hours of core services that were provided to children each week. The program was designed to deliver 20 hours a week of direct intervention service to each participant. This figure was based on a minimum national recommendation from the National Research Council. Strong consensus in the scientific community maintains that intensity of intervention is a key variable in outcomes of children diagnosed with ASD. At the outset of the program, it was an uncertainty if providers could overcome geographic challenges found in Montana to deliver a sufficient number of intervention hours.

Data were collected on this variable from the State computer information system invoicing and reimbursement information submitted by providers. Given the business rules around billing, this data should be viewed as a conservative estimate of program time provided. For example, some participating children were required to bill insurance companies for some hours of program services and those hours would not be represented here. In addition, providers encountered many challenges in providing the large numbers of hours of services required for program participation. Challenges include: finding, training, and maintaining qualified direct service providers (CATs) and finding time in the child's/family's schedule particularly if the child was school-aged. While these are still challenges today, providers were able to provide an intensive program. Table 1 presents the average number of hours per week per year of intervention that CAW participants received. The data are presented by type of service: case management; Program Design and Monitoring (PDM), and direct autism intervention service (CAT).

Table 1. Average number of hours per week of CAW service by year and total.

Service	Year 1	Year 2	Year 3	Total Program
Case Management	2.1	2.1	2.1	2.1
PDM	2.1	2.2	2.2	2.2
Direct Service/CAT	16.11	16.22	15.79	16.04

In addition to these being underestimates, it should also be noted that the range of average hours varied widely by participants, with some children billing for as little as 4.7 hours a week and some children billing for as many as 31.95 hours a week.

Regardless, data clearly illustrate that providers of CAW services delivered a significant amount of programming per week to participants. When all CAW service types are combined, children billed for, on average, 20.34 hours a week, meeting the prescribed number of hours.

The other question posed for program evaluation is: “Are interventions developed for children served by the CAW implemented with fidelity?” The term “treatment fidelity” describes the idea that interventions (i.e., teaching practices) were implemented as planned or as described in scientific literature. Fidelity is essential to understanding key ingredients in the program as well as program outcomes, but is also considered a key component to good outcomes (Strain, 2011) as well as to replicability, sustainability, and scaling up of the program (Fixen & Blasé, 2009).

Given the amount of training and program development that was required to develop and implement the CAW, the most direct measures of fidelity were conducted live with service providers during technical assistance visits. Through these visits significant feedback, modeling, and correction was provided helping to ensure that interventions were implemented with as much fidelity as possible. However, in the future, to insure program outcomes, more standard measures of fidelity will need to be developed and used.

The CAW is a program that uses Applied Behavior Analysis (ABA) as the science and philosophy behind program decision making and specific intervention techniques. The National Standards Project and The National Professional Development Center have both reviewed the scientific evidence to determine which specific ABA interventions have an evidence for use with children with ASD. There are 27 interventions that meet their criteria. These interventions likewise form the core of interventions used in the CAW. Table 2 lists these 27 interventions and shows the order of the intervention used in the CAW ranked by frequency of use.

Table 2. Rank order that an intervention was used in the CAW (by frequency of use).

Rank Order	Evidence-based Intervention
1	Prompting
2	Reinforcement
3	Discrete Trial
4	Visual Supports
5	Modeling
6	Differential Reinforcement
7	Response Interruption
8	Schedules
9	Task Analysis
10	Antecedent Based Intervention
11	Extinction
12	Naturalistic
13	Self-management
14	Functional Behavioral Analysis
15	Time Delay
16	Parent Implementation
17	Social Narratives
18	Computer Aided Instruction
19	Functional Communication
20	Video modeling
21	Pivotal Response

22	Social Skills Groups
23	Story-based Package
24	Peer Mediated
25	Structured Work
26	Speech Generated Devices
27	Picture Exchange

This data indicates that the most commonly used interventions in the CAW have a strong base in both ABA and in scientific literature. However, evidence in Table 2 also suggests that more program emphasis needs to be placed on social interventions, behavioral supports, and communication interventions in order to better address core symptoms of ASD and on parent training for sustainable outcomes.

Taken together, the number of hours of service provided, the fidelity enhanced through technical assistance, and utilization of evidence-based practice all indicate that CAW providers were able to provide a program like the one proposed. However, it should be noted that to enhance and maintain program quality several future steps are warranted. These include: development and implementation of a more formal fidelity measure; more support in development and implementation for interventions for parent training, social interventions, behavioral supports, and communication and development of a CAW manual to systematize program development that has taken place to date.

Evaluation: Child Outcomes

The two questions the *Evaluation Plan* asks in terms of child outcomes are: 1) “What progress do children make while involved with this program?” and 2) “Do children who participate in the CAW make more progress than those who do not?”

In order to answer the question “What progress do children make while involved with this program?” data from several sources were collected. Data were collected on symptom severity, developmental skills and functional skills. Data collected used multiple types of measures including standard, norm-reference assessments as well as more observational measures.

Symptom severity was measured by the Childhood Autism Rating Scale (CARS). The CARS is a well-established tool with well-regarded psychometric qualities. Often used as a diagnostic tool, in the CAW evaluation the CARS is being used as a descriptive outcome measure. The CARS yields three descriptive categories: minimal to no symptoms (non-autistic); mild or moderately autistic; or severely autistic. Table 3 presents child outcomes according to exit scores on the CARS.

Table 3. Percentage of CAW Completers by CARS Outcome Descriptions

Non-autistic	Mild to Moderate	Severe
48.5%	28.6%	22.9%

According to CARS scores, nearly half of CAW participants no longer exhibit symptoms that would result in an ASD diagnosis. This should be interpreted with caution, as ASD is a life-long disorder and it may be that as these children age, they may need additional supports or service.

Another widely used outcome measure for programs that treat children with ASD is school placement. At exit from the CAW, 65% of children were in general education services; 32% in Special

Education services; and 3% were home schooled. A third outcome measure commonly measured is community access. At exit from the CAW, 65% of participants had full community access, 23% had moderate community access, and 15% had limited access. Finally, eligibility for other DDP services was measured. At exit from CAW, 77% of participants were no longer eligible for DDP services, whereas 23% were.

No individual outcome measure should be used to evaluate the overall effectiveness of the CAW. Rather, a composite measure combined from the above measures is more likely to provide an authentic measure of CAW success. Each measure (i.e., CARS score, school placement, and community access) were all assigned a “best outcome” designation. Best outcome on the CARS is non-autistic; best outcome for school placement is general education; and best outcome for community accessibility is full community access. Next, the number of participants who reached best outcomes in all three measures was counted as was those who meet best outcomes in two, one, or none of the categories. Table 4 presents the percentage of CAW completers by the number of best outcome categories they reached.

Table 4. Percentage of CAW Completers in Accordance to Number of Best Outcomes Achieved.

Number of Best Outcomes Achieved	Percentage of CAW Completers
3	32%
2	36%
1	16%
0	16%

Data in Table 4 indicate that 84% of CAW participants reached a best outcome in at least one of the categories. Only 16% failed to reach best outcome in any area. It should be noted that in 16% of children who did not reach a best outcome in any single area, all showed growth from their baseline. Further, baseline measures of children did not determine outcome. This failure to predict outcome is a field wide experience and worthy of future study.

In terms of functional measures, significant changes were seen in functional skills. Table 5 shows outcomes for toilet training and communication skills.

Table 5: Pre-Post Comparison of Functional Skills for CAW Completers

Functional Skill	Pre-CAW	Post-CAW
Toileting Skills	30% Trained	72% trained
Communication Skills	33% Verbal (50 or more words)	81% Verbal (50 or more words)

Data in table 5 indicates that large gains were made in functional skills for CAW participants.

In order to answer the question “Do children who participate in the CAW make more progress than those who do not?” in a definitive way, a randomized control trial experiment would need to be conducted. Due to the fact that the CAW is still in the development stage, it is premature to conduct such a study. This type of study will be warranted once the CAW model is fully developed and each program component has been individually studied and shown to be effective.

Other ways to answer this question were also considered. A comparison between CAW participants and waitlist control was considered; it was too costly to collect information on children on the

entire waitlist. An alternative, matched comparison between CAW participants and children on the waitlist was also considered; however, the only data available for children on the waitlist was for those receiving service through other DDP programs. Given that 75% of the CAW participants who finished the program no longer qualify for other DDP programs, any comparison between these groups would be skewed to a degree that it would no longer be valid.

However, this question was addressed in several ways, using participants themselves as their own controls. The proportional change index (Wolery, 1983) compares the rate a child was developing before intervention with the rate that child developed with intervention. A change in this metric suggests the intervention is having an effect. Using the proportional change index, it was determined that on average before enrollment in the CAW, children were learning two weeks of information for every month of living. During CAW participation, children were learning 6 weeks of information for every month of living. Such a dramatic positive change is evidence the CAW is having an effect on children's learning.

Additionally, other CAW outcomes (e.g., changes on standard measures like the CARS) indicate substantial changes in children that, without intervention, would not have occurred. Similarly, these outcomes compare favorably with national published outcomes from other high-quality programs for children with ASD. Some of these programs conducted comparison studies that indicate that this type of program at this intensity does yield outcomes in children that are significantly different from child who did not participate in program activity. Thus, while we cannot as of yet definitively answer this question, the available data as well as published data from similar programs suggests strongly that program participation is responsible for the strong child outcomes.

Evaluation Focus: Family Outcomes

The two questions the *Evaluation Plan* asks in terms of family outcomes are: 1) "What impact does the child involvement in this CAW have on the family as a whole?" and 2) "Are families satisfied with waiver services?"

In order to answer the question "What impact does the child involvement in the CAW have on the family as a whole?" We have little empirical data to answer this question. Anecdotally, families have had a range of responses to CAW participation. For a minority of the families, the demands of 20 hours a week and the demands of an in-home program have been stressful. For others, the program has benefited all aspects of family life; including those who report they are now able to "be" a family and participate in activities together. For some, the only stressful aspect of the CAW was the transition away from CAW services. This evaluation questions will be more thoroughly addressed with Cohort 2.

In order to answer the question "Are families satisfied with waiver services?" data was collected by the DDP quality assurance process as part of their annual survey for federal reporting. Only data collected in the last year of CAW participation is presented here. Overall, 75% of participating families were either very satisfied or satisfied with the CAW service; 9% were neither satisfied nor dissatisfied and 17% were either somewhat or very dissatisfied with the program. Satisfaction was not tied to child outcome, as seen in Table 6 below.

Table 6: Percentage of Parent Satisfaction Based on Child's Exit CARS Score

CARS Outcome	Very or Somewhat Satisfied	Neither Satisfied or Dissatisfied	Very or Somewhat Dissatisfied
Non-autistic	73%	9%	18%

Mild or Moderate	100%	0%	0%
Severe	75%	0%	25%

Thus, the majority of the parents were satisfied with the program and program satisfaction was in no way tied to child outcome.

For parents who provided additional feedback, the most common comment was that the parent was very happy with the program (e.g., parents said they were “thrilled” or gave the program “an 11 out of 10”). The next most common comments were issues with personnel followed by logistical concerns and concerns about the direct service providers’ skills (availability, training, expertise and turnover were all cited as concerns with direct service personnel) and the least common comment made was about fears for the future.

Evaluation Focus: Program Outcomes

The question asked in this area of the *Evaluation Plan* is “How successful in the CAW?” This evaluation question has significant overlap with the question regarding child outcomes addressed above. Based on the child outcomes and the parent feedback, it is clear that the CAW program is a remarkable success.

Evaluation Focus: Provider Outcomes

The question asked in this area of the *Evaluation Plan* is “What do service providers think about the CAW?” This evaluation question was assessed continuously throughout the first three years of the CAW. Although service providers face multiple challenges in designing and implementing this program, they are pleased with the program. Most providers have significantly increased their infrastructure for serving children with ASD in intensive, behavioral programs. While providers are challenged with finding, training, and maintaining direct care providers as well as with delivering services over great distances, the providers are in favor of not only maintaining the program but in significantly expanding it to offer the same life-changing opportunities to other children with ASD and their families.

Summary and Conclusions

While the *Evaluation Plan* did not include questions about fiscal expenditures or cost savings of the CAW, it is important to address this issue in broad strokes. In terms of expenditures, each participating child has a budget allocation of approximately \$43,000 per year for each of the three waiver years. The appropriation to DDP for the CAW each year is \$2.1M with the State general fund portion being \$709,000. The CAW is the payer of last resort, meaning that if there are other ways to pay for the services those funds must first be accessed. Many participants of the CAW were also eligible for autism treatment through health insurance. In these cases, the families’ insurance carrier was billed first, and any remaining costs were billed to the CAW. Further, insurance companies view billing information as proprietary, and thus are not available for analysis. However, of the money expended by DDP, 91% of the total billed went to direct core services and 9% went to purchase ancillary support services such as adaptive equipment and environmental modifications, respite, transportation and therapies.

Equal caution must be used when projecting cost savings. Ganz (2006) projects that the lifetime cost for an individual with ASD is \$3.2M. These costs are associated with family members missing work, increased cost of medical expenses, and the cost of therapies and other treatments. Ganz (2006) estimates

the annual national cost for all people with ASD to be \$35B annually. However, he notes that as children access appropriate treatments, costs for individuals are likely to go down. There have been immediate savings from CAW participants. Sixty five percent of the CAW participants access general education. Without CAW services, it is most likely that these children would be in Special Education services—this educational placement is the source of immediate savings. Similarly, 75% of the children are no longer eligible for DDP services. Without the CAW, these children would likely be eligible for DDP services. The children no longer eligible for DDP services are another source of immediate savings. Finally, 48.5% of CAW participants have experienced a significant reduction of symptomology. While these children may need additional services in the future, at the completion of the CAW, their functioning level reduces the need for families to miss work or to fund additional therapies. This savings, while challenging to predict, will be in the millions of dollars.

In summary, the first three years of the CAW and the first CAW cohort was incredibly successful. While challenges still exist and model development and training are still ongoing needs, the outcome measures are on par with published results from the best national programs.

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Appendix A

Map of CAW Cohort 1 Family Locations

COHORT #1 - ★ REPRESENTS LOCATION OF FAMILY/FAMILIES

